

Life Story Sharing: A Therapeutic Intervention in Palliative Care

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Abstract

This chapter presents a personal reflection by Sharing Stories for Wellbeing (SS4WB) workshop facilitator and programme founder Miranda Quinney with observational input from Alison Ward and Jane Youell of the University of Northampton following the University's evaluation of the programme in May 2015. SS4WB provides facilitated storytelling sessions in palliative care. Workshops foster life-story discussions which participants share with the group, that are delivered in a non-linear style and are based on themed topics. Groups are supported by hospice staff, who provide both pastoral and clinical care. Informal observational feedback suggested that the potential benefits for participants were improved self-esteem, feelings of being valued and of being listened to at a time of personal distress. The running of new SS4WB sessions at Watford's Peace Hospice Care gave the opportunity to conduct a formal evaluation and to understand the potential value of participation. The evaluation was conducted over five weekly sessions between May and June 2015.

Four broad evaluation themes emerged: 'pleasure'; 'what makes you, you'; 'more than just a patient'; and 'benefits beyond the group'.¹ Participants reported enjoyment and felt a sense of autonomy and control in deciding on the stories shared². Sessions provided an opportunity for social engagement, giving a sense of togetherness and were a means to explore the participants' sense of self and feelings of being valued as a person, not a patient. The telling of biographical reminiscences was reported to bring positive reminders of changing times and lived experiences. Workshop engagement also led some participants to experience improved confidence and reduced social isolation, as evidenced through staff and family views and participation in new activities. SS4WB enables people in palliative care to share their life-stories in a supportive and safe environment. Participation can have positive outcomes fostering choice in the stories shared which then engenders a sense of autonomy and control, reminiscences can also bring feelings of value and self-esteem.

Key Words: Storytelling, palliative care, wellbeing, life story, training.

Banksy is often credited with saying: 'They say you die twice. One time when you stop breathing and a second time, a bit later on, when somebody says your name for the last time'.³ There is confusion about the exact origin of the quote, some say the words were those of Irvin D. Yalom, others David Eagleman, and yet others that

the words have been passed down through the ages. Irrespective of its source, it is the sentiment behind it that resonates.

Life Story Sharing is a way of delaying that second death by keeping the story alive. By sharing individual life stories towards the end of a life with friends and family, the teller takes control of the preservation of their part of the family's history for future generations. Whilst the practical results of this process are obvious, it is the unintentional but powerful effect on the wellbeing of the teller that is being embraced by the Britain's hospice community. Over the past year over thirty hospices based in England and Wales have asked for training in the techniques developed by SS4WB when running Life Story Sharing workshops. The aim of this chapter is to share some of the learning gathered in the course of developing the workshops and when evaluating the programme. Pseudonyms are used for workshop participants where necessary to maintain confidentiality.

1. How Did the Programme Come About? Miranda's Story

The eldest child of Anglo/Iranian parents, I have grown up with the stories of their youthful globe-trotting adventures. What I hadn't realised was that so many of their friends had also had extraordinary adventures but not until I heard about them as part of a eulogy. The stories were thought-provoking and often led me to reconsider my perception of the protagonist. I wished that I had had the opportunity to hear those stories before death, at a time when the teller was still around to talk to and to question.

I soon found that I was not alone – others in the congregation were often also hearing these stories for the first time. I set up a service to record, write and publish personal life stories. I had a lot of willing clients who wanted their parent's stories written, but I came up against a problem, a reluctance or taboo to talk about issues related to death as this made the topic more real⁴. Whilst family and friends were keen to commission me to write the life stories of their parents and grandparents, the parents and grandparents sometimes interpreted the invitation to tell and record their stories as an indication that there was a general consensus that they were about to die. Talking about death and dying is something the British public find difficult to do, so much so that Britain's National Council for Palliative Care has spearheaded Dying Matters Week, a public awareness initiative to encourage people to talk about death and dying. Despite this many remain reluctant to discuss the subject and the practical result, in terms of recording their life story, was that the story was not told, shared or recorded. We were back to the first public sharing taking place as part of a funeral. I struggled with how to overcome this powerful superstition but could not see a way through.

Several years later I was presented with an opportunity. The circumstances were quite unexpected, some might say morbid. A close family friend was diagnosed with cancer and had a short life expectancy. She was admitted to my local hospice. I knew little about hospices or the hospice movement. I had never heard of palliative care. I

will openly admit that I was terrified at the prospect of my first visit to see her there. Everything that I had heard about hospices suggested that they were places to be avoided; the final stop before death, the Hotel California of the medical world where you'd check in but never out again⁵. I was taken to the In-Patient Unit. There were nurses and medical equipment, but there was no *ward*. Each patient had a private room, well decorated, comfortable and, most importantly, there was none of the antiseptic smell so often associated with hospitals and care homes.

As I visited my friend Beverley again and again over the next few weeks I was impressed by the level of care she received. When she died a few weeks later, I wanted to do something for the hospice which had cared for her so magnificently. I approached the hospice manager and offered my services as a biographer. This entailed helping patients to record and share their life stories. As hospice patients, all workshop participants were aware that death could be imminent but at least the psychological impediment of talking about death was removed.

I received a speedy and positive response to my offer and was surprised to be introduced to the Hospice Day Services Manager. My limited experience of the hospice to date was of the In-Patient Unit, which had supported my assumption that all hospice service users were on the point of death. My assumption was wrong. I was shown around the hospice and it was explained to me that the In-Patient Unit constituted a very small part of the services offered. Indeed, at that particular hospice, a far higher proportion of time was spent working out in the community with the patients in their own homes. In addition, they also offered Day Care support for both patients and carers. Furthermore, the range of individuals entitled to benefit from the services offered by the hospice was far broader than I had imagined. Rather than working only with those with a very limited life expectancy, the hospice also had a variety of services that they offered to the patient's family and support networks, including respite care and ultimately bereavement counselling. The next surprise was to discover that it was not just those patients with an extremely short life expectancy who could go to the hospice and ask for support. The day care service's key criteria was that a patient should have a limited life expectancy and in some cases this could be three, four or five years. It was in this later context that the hospice wanted to take up my offer to write life stories; as a service for patients and carers using day care services.

2. The Programme

I was unsure as to the precise form the service would take. One thing however was clear, the service would differ from that offered by narrative therapists where clients are encouraged to organize and give meaning to their experiences through the medium of story with the intention of further shaping their lives and relationships.⁶ As a storyteller and biographer, I was not a trained counsellor, nor was I an oral historian recording full length biographies to be archived for future research. I experimented with different ways of encouraging people to tell. Working one to one

had the advantage that both I and the participant could really concentrate on the stories being shared but had the disadvantage that the participant often lapsed into a form of narrative which asked for a therapist's response. Inviting individuals to share anecdotes with me on a one-off basis as part of a large group activity did not give the activity sufficient weight.

What was eventually devised was a workshop programme run over a five-week period for a small closed group of up to six patients. Keeping the group closed preserved the group dynamic and provided a sense of safety for participants when sharing their stories. Whilst holding the workshops in series, rather than as a one-off event meant that participants sometimes missed sessions, the benefit was that they got to know each other well over the weeks. It soon became clear that given the diverse range of backgrounds of participants, following a linear format for life story sharing would be problematic. Participants came from widely differing cultural and socio-economic backgrounds, I could make no assumptions about the experiences of their past. Accordingly, I turned to themes, with a simple theme for each session to which I hoped each participant could relate. Even then I had to consider carefully whether the themes carried with them an obvious element which might result in a participant feeling uncomfortable about the sharing process. For example, on one occasion I suggested the theme of holidays, assuming this would be relevant to all participants. Observing the session, I soon realised it had been a mistake; the lady who followed the story of a grand world cruise with her camping trip looked uncomfortable and apologetic. Next time around, I changed the session that had been about holidays to one entitled celebrations. That worked a lot better. Other themes I used include the senses, nature and colour. At the end of each session, I would set the next week's theme and participants came with a story to tell from any stage in their life. The result was participants chose which stories to share from any period of their life. The experience felt positive and uplifting.

Each workshop was an hour and a half long, run at the same time and at the same place on consecutive weeks giving the programme consistency. Whilst I facilitated the workshops I also received supervision from the hospice's senior social worker. Access to supervision was crucial. As a palliative care specialist she was available to provide emotional support to participants and also to me as a facilitator.

As facilitator I took long-hand notes of the stories told in each session. As I did not record them electronically, they were not verbatim transcripts. My reasons for this approach were simple; firstly, the technology itself can be intimidating and I am not very good at managing it, secondly the time and therefore cost involved to type a verbatim note is significant and could have been enough to scupper the entire process. After each session I typed up my notes into a simple word document, trying to be as faithful as possible to what I had been told. I did not conduct any additional research, fact check, or make any observations or judgements concerning what I had heard.

Following the final session each participant received a simple folder containing type written copies of the stories that they had told. At the start of the workshop series I made it clear that the notes were my best effort at writing down what they had said. I explained that I would not be conducting any additional research or checking their account of events. There was an acknowledgement that I may have misheard certain statements but that any mistakes were unintentional. I included a disclaimer with the final written format. As it turned out, the documents were received with delight, none of the participants asked for changes or corrections to be made.

3. Next Steps: Sharing the Programme

In observing the weekly sessions, the social worker soon took me to one side and asked whether I had any idea what I was doing. A flutter of fear coursed through my body as I worried that perhaps there was some protocol I was unaware of that applied in the palliative care sector about which I knew nothing. After all I had created a programme from grass roots rather than adapting it from an existing activity. I felt instinctively that what I was doing was good. Patients seemed to enjoy it and didn't want to leave at the end of each session. However I was acutely aware that I had no training as a therapist or in any form of counselling, I was very aware that there was no obvious precedent for what I was doing and that as a result there was an element of creating the process as we went along. Quickly responding to the concern in my face, the social worker smiled and said

I'm watching the patients both inside and outside of these sessions. I can see that they are responding very well. I can see them becoming more confident, their self-esteem is growing, I'd say that their general wellbeing is improving and I think that these life story sessions are a key factor. We need to share this with others.⁷

My goal from that point was to find a way to make life story sharing sessions available in other hospices. This was not something I could do alone. A solution was to train a team of practitioners who, in turn, could train their colleagues. The resulting cascade could then make it possible for every hospice patient to have the opportunity to tell and save their story. In 2014 Hospice UK, the national charity for hospice care displayed a poster about the work at their annual conference. They went on to invite me to speak at their 2015 conference, which provided an international audience of individuals responsible for the strategic development and care in 220 or more hospices. Persuading the chief executives of these hospices to adopt a group storytelling programme as part of their in-house services for patients was going to need more than enthusiasm and anecdotal feedback. I needed evidence.

An introduction was made by Hospice UK to Alison Ward of the University of Northampton which provided the solution to that need. Alison agreed to take my

evaluation proposal to her team and they in turn approved the funding to conduct an evaluation of the sharing stories for wellbeing programme.

A. Evaluation

Alison Ward and colleague Jane Youell used a mixed method approach in conducting the Evaluation.⁸ Patients (n=5) were asked to complete a paper questionnaire prior to the commencement of the workshop series and a second paper questionnaire was completed after the final workshop had taken place. Two participant observations were undertaken by the evaluation team; one mid-way through the workshop series and one at the end. Finally, participating patients (n=3), hospice staff (n=3) and a patient family member (n=1) attended face to face interviews with the researchers.

Following presentation of the evaluation outcomes at the 2015 Hospice UK conference, I was invited to run a series of one day master classes for clinicians, spiritual advisors, counsellors, palliative care nurses and volunteers interested in offering life story sharing in end of life care. Currently, as I write this, over ten per cent of the UK's hospices now have access to a trained life story group facilitator and the number continues to grow. International interest in the programme is also growing with palliative care professionals from Singapore, Hong Kong and Canada also expressing interest in developing the programme for use in their own practice areas.

4. Why Do It?: The Observations of Jane Youell and Alison Ward of Northampton University

Analysis of the results, feedback and observations supported the key themes we had observed in the course of running the life story sharing workshops:

- Participants enjoyed the sessions;
- Sessions provided an opportunity for participants to be truly heard;
- Participants experienced a renewed sense of identity beyond the patient;
- Participants felt that the sessions were one of the few situations where they were fully in control.⁹

A.1. Enjoyment

Groups were closed with no more than six members, each of whom joined the group following referral from a hospice clinician. The closed group format, as Mary Anne Boyd suggests, guaranteed no new additions to the group in the course of the workshop series, thereby maintaining the group dynamic, promoting group bonding and cohesion.¹⁰ Referral into the group by palliative care staff helped ensure an appropriate mix of attendees. There were no strict participant criteria applied other than an acknowledgment on a practical level that participants would need to be able to communicate verbally. Attendees of the hospice day care were offered leaflets about the programme and invited to apply to join the next available workshop series.

Coordination was carried out by the hospice creative activities coordinator. Limiting the numbers helped create a supportive environment. What we observed was a rapid development of friendship bonds. Participants seemed enthusiastic about catching up with each other from week to week and some arranged to meet each other socially between sessions. The development of social networks, the enjoyment of meeting people and developing friendships was emphasised by the evaluation, where the sessions were reported to be fun and engaging and their friendship bonds increased confidence and rapport with others.¹¹

As the weeks passed the participants became more attuned to the needs and interests of their co-participants. At most sessions, participants were able to share two or more stories. Whilst the first tale was usually something prepared in advance of the session, the second and sometimes third stories were often inspired by the stories shared by co-participants. One example took place in an introductory session where participants were encouraged to introduce themselves to one another by telling a story inspired by something they were either wearing or had with them. Jane introduced herself to the group using her art gallery membership card. Henry followed on pulling a postcard from his wallet of a painting in an exhibition he had been visiting when he met his wife. On another occasion George told his story of celebration describing D-Day in his home village. Alice followed on with her experiences of Liberation in Belgium. George listened with rapt attention; he had never heard a first-hand account of the end of the War from someone from another country.

Participants clearly enjoyed both telling their own stories and listening to those of others in the group. Where some participants in the first session had expressed difficulty in finding a story to tell, by session three they were clearly engaged, allowing the stories to flow, one leading to the next. The role of the facilitator throughout was to ensure all participants were heard and that there was some link to the theme for the week. From time to time the discussion would take an unexpected turn, as in the week when the theme of celebrations led to a family visit to Mexico, a discussion of the Day of the Dead and then a very upbeat discussion of the variety of coffins on offer. This was an occasion when the facilitator turned to the supervisor for emotional support. By the end of the workshop series, trying to draw the sessions to a close had become quite challenging.

A.2 Therapeutic Activity vs. Therapy

The key difficulty with running a closed group, particularly in palliative and end of life care is that group numbers can dwindle to just one or two. Participants may be too unwell to attend or may have died in the intervening week. As a facilitator with a small group of one or possibly two, it was important to guard against drifting away from the therapeutic activity into offering narrative therapy. With just one participant working with the facilitator there was a real risk that the self-censorship which existed in the group environment no longer applied. It was harder to stop the

story from becoming more self-reflective with the teller potentially turning to the facilitator as a counsellor or therapist. Using a thematic approach to each session helped to avoid this pitfall. Even where just one participant attends, themes such as the senses, colour and nature can all be extended to encourage a series of linked stories and allow the facilitator to redirect the participant away from a timeline.

B. Identity Beyond Being the Patient

Post session feedback suggested that participants noticed the very real interest we as facilitators had in their stories, they felt that they were being seen as individuals rather than as patients. This became an important aspect of their enjoyment of the programme. As a facilitator I had to find a way to avoid focussing on the illness. The solution was quite simple, to not be told the diagnosis or prognosis of any of the workshop participants. Sessions started not with the more usual 'how are you?' as that invites a response reverting to illness, but instead something on the lines of 'how lovely to see you' and a quick sidestep to the theme for the day's session. This way it became easy to see past the illness to the person and an equal. In the process, the patient becomes a storyteller and their identity goes beyond that of the 'patient', finding their connections as mothers, sons, teachers, etc. One memorable session led to sharing recipes where one participant, Jean, found great joy in sharing her best cake recipe and, in a later session, bringing in a cake to share with the group. This not only brought with it a sense of purpose but also a sense of self-identity as a provider and baker, linking to Jean's former notions of self and not just her current identity as a patient¹².

C.1 Being Heard

Many of the participants joining a life story sharing group announce at the start of the first session that they have nothing to say and question why anyone would be interested in their stories. When asked why they have chosen to attend, they might explain that they would like to listen to the stories others have to tell. They simply lack or have lost the confidence to tell their own story, to know that it will be interesting and of value. The key is to encourage them to tell. The story sessions can develop a sense of self-worth and confidence in being given an opportunity to have your story and your voice heard. This has a strong association with the patient vs. person concept already discussed, as the story process encourages people to share aspects of their life story and be more than the person with an illness and instead draw on care which is multi-disciplinary and help to maintain identity.¹³ Being heard is not just about sharing your stories but also knowing that these stories will be heard after the person has passed away, giving a sense of legacy or passing on to the next generation. This feeling of sharing experiences before they are lost was expressed by participants in the evaluation who saw value in telling their story, as one storyteller stated, to 'pass them onto future generations of the family'¹⁴. This not only provides a sense of self-worth through passing on lessons learned but also

strengthens self-identity as the person can be seen as more than their family role-identity through the stories.¹⁵ Furthermore, sharing the stories can have a profound effect on the way the clinician or care giver sees the patient. On one occasion, George was wheeled into the session by one of the hospice nurses. She asked if she could stay for the session and all present gave their consent to this. She went on to hear George tell tales of his days as a young competitive cyclist regularly travelling hundreds of miles on a bicycle with solid wheels. The nurse was fascinated and acknowledged that this made her consider George in a new light. She and George went on to spend quite some time together looking through his cycling photos. I often wonder if hospital based geriatric care would change if nurses could be given the opportunity to hear their patients 'stories'?

C.2 Finding the Time to Listen

Participants often say that the stories they tell in the group have not been shared for many years, if at all. They explain that they are concerned about encroaching on the busy lives of friends and family. Having now listened to hundreds of stories, my belief that each of us has a story to tell is stronger than ever. Finding the space to tell and listen is key. In one story that stands out Clara told of her time working in a mission led school in Kenya in the 1960s. She described a weekend safari visit when her husband needed to pay a visit to the toilet after dark. She begged him to stay in the hut and use the potty provided for occasions like this, but he refused. When he returned a little later she breathed a sigh of relief. The next morning the camp director ushered her and her husband to see a series of lion paw prints which had appeared overnight, they travelled the length of the camp and circled the toilet block. Clara's husband had been lucky to survive.

After I heard this story, told beautifully with a lot of description and emotion, I asked whether Clara had shared it with her young grandsons. 'Oh no' she answered 'they are all too busy to listen to me'.¹⁶ I hope that my transcript finds its way into their hands at a time when they can ask Granny more questions and that the first time they hear it is not in a eulogy.

C.3 Listening Properly

Persuading a participant to tell their story is just one part of the process, listening to it is the other. So often we only half listen, thinking about the question we would like to ask, what story we will tell in response, worrying about the text that just came through on the phone or what has to be done next rather than paying full attention to what is being said. Listening properly is a skill many of us have fallen out of the habit of using. Storytelling can be beneficial for both the storyteller and the listener, with both being active in the telling process.¹⁷ The creative techniques employed in Sharing Stories help to develop active listening skills, enabling the teller to be really heard, which is crucial to the story sharing sessions.¹⁸ However, trying to do this in

a group can be difficult. To address this I introduce a telling and listening technique into the session often used in drama schools called *mirroring*.¹⁹

Mirroring involves splitting the group into pairs. In each pair participant X listens closely to the story told by participant Y without interruption. X and Y then reverse roles with Y listening to X's story. Each having heard the other's story, then tells the story that they have heard out loud to the rest of the group. Accordingly X tells Y's story and Y, tells X's story. As a result, the level of concentration used when listening is significantly higher than that usually adopted. Most participants want to make a good job of retelling the story that they have heard. They want to honour both the words and the spirit of the story. Accordingly, I usually allow for a short period for clarification between partners before asking the whole group to feed back the stories that they have heard.

Watching the process, I notice that tellers often ask for an acknowledgement from their partner either during or after the retelling that the story they have re-told was largely accurate. The confirmation that usually comes provides a sense of achievement and gives the teller confidence to proceed. Where there are inconsistencies, then this moment provides an opportunity for any corrections. This is important given our predisposition as listeners to personalise the stories we hear, quite often unknowingly. On one occasion Y told X's story about a box of buttons that his grandmother had had. When he finished the retelling, X thanked Y for honouring the story whilst also adding that the original story had in fact been about a bag rather than a box of buttons. Y then realised that he had personalised the story recalling a box of buttons his own grandmother had had.²⁰

Mistakes of this kind are not uncommon and it is the job of the facilitator to ensure that there is space to rectify any misunderstandings or glaring inaccuracies. Whilst this often happens naturally, on occasion it is important to intervene. This can be done once the teller has finished recounting their partner's story. In one session the teller referred to his partner as Yvette rather than Yvonne throughout the retelling. His partner did not intervene or make any comment. It was my job as facilitator to set the record straight but only at the end of the telling thereby ensuring that the teller did not lose confidence.

It is also sometimes necessary to intervene where X tells Y's story but does so without honouring its spirit. One memorable session involved stories of taste. Marion told her story about the first time she went to the market in South Africa and saw an unusual prehistoric looking fruit. When she opened the fruit, she discovered its creamy white interior and delicious taste. This was her first avocado, a fruit she had never eaten before. Marion described the look and feel of the fruit to her partner Mary in detail going on to express her surprise when she returned home some ten years later and was amazed to find the same fruit on sale in the supermarket of her local town.

When it came to Mary retelling the story she provided a short summary – Marion tried her first avocado in Africa and was then surprised to find them in the

supermarket when she returned to England.²¹ Factually accurate, the story had lost all its beauty. Did Marion feel heard? Probably not. As facilitator it was my job to capture and air that story in the spirit in which it was told. Having monitored the group as the mirroring between partners was taking place I had been able to overhear elements of each of the stories being shared, including this one. I was therefore able to supplement the telling after its initial delivery honouring the story as best I could. Going forwards, I was careful to ensure that Mary and Marion were not always partnered together. By maintaining a small closed group, it is possible to develop a knowledge of the strengths and weaknesses of its participants making it easier to ensure that each of its members is properly heard.

Indeed, as the sessions progressed, some groups like the discipline of mirroring, others preferred to abandon it and tell their own stories directly out into the group. Both approaches are perfectly fine and the approach the facilitator adopts will depend on the dynamics of the group in question. Where the group reduces down to one participant, then rather than mirror the single story, the storytelling usually develops organically with the facilitator listening carefully allowing the participant to speak before asking more questions with a view to encouraging another story. On these occasions a 90-minute session can be quite exhausting and as facilitator I am usually prepared to share a few of my own stories in order to allow some recovery time for the sole participant.

C.4 Recording the Stories

Writing up the stories is the final step in ensuring the stories are heard. I take notes throughout each session; other facilitators record the sessions digitally. Producing the stories as something tangible is a powerful physical reminder that the story has been heard. The methodology for recording the story appears to be less important than the end product. Again I take a practical view. Transcribing audio recordings verbatim is costly and time consuming. Many hospices have limited resources and requiring this approach may be the reason why a life story sharing programme does not get adopted. I find that a simple printed document is all that is needed. Provided the patient is aware of the limitations, they are comfortable that reasonable care has been taken to accurately write up the stories shared each session. The participants are often delighted that someone has gone to the bother of writing up the stories for them. In addition to verbally explaining the process and providing patients with a written outline of the process at the start of each workshop series. We also use a series of disclaimers reminding patients that the story has been written down as it is heard, without interpretation, research or reflection and that any inaccuracies are unintentional. The following is a typical example:

Notes/disclaimer

I hope that I have got the details right in this. I have not checked or verified the accuracy of any of the information contained in it - it is purely a representation of your story, as I heard it.²²

This seems to be sufficient to satisfy most participants. I do not offer to carry out additional research or check the accuracy of the tale I have heard, if a participant wants to present a fabrication, then that is their choice. It is not the intention behind these sessions to produce a factually accurate biography, indeed one person's perception of the story will often be quite different to that over another who was also there. That said, given memories are often unreliable and the stories shared may be factually inaccurate and inaccuracies are not going to be corrected, other members of the participant's family group cannot be assumed to have the right to access them

D.1 Control

All participants in the story sharing groups will be drawn from the hospice's palliative care community. It follows that each has a diagnosis, or in the case of a carer's group, is caring for someone with a diagnosis. In either case, the schedule of their day to day life is often heavily influenced by various practical medical processes running concurrently.

A key theme to emerge from the evaluation data was a resounding recognition that participation provides an opportunity for patients to take back control of at least a part of their life – their story.

Lisa is categorical, 'It was my time to tell my story'.²³ Lisa's nephew was asked to provide some feedback on the effect attendance at the sessions had had on his aunt and he too noted that the sessions appeared to have played a part in helping her to resume her pre-illness identity. This is supported through the programme evaluation, which found the storytelling enabled a sense of feeling valued and having choice in the story you retold. One member of the hospice staff reported that one of the storytellers

... felt she was a bit more individual again, a bit more in control because she was actually telling people about her life story... she felt she was doing something worthwhile. That's what she described it as and she felt humble because other people were interested in it, because other group members were asking her about it.²⁴

The accuracy of the content of the story is largely unimportant; the fact that the patient can tell the story without worrying about its accuracy removes a barrier and encourages fluency. In the first of the workshop sessions I run through the ground rules for subsequent sessions:

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- The facilitator will write up the stories that are told to the best of their ability without conducting any additional checks or research;
 - Full copyright for the stories lies with the teller;
 - Confidentiality in relation to the stories told will be maintained by all attendees.

D.2 Writing Up

The limits to the writing up service are covered in the preceding paragraphs. Before the mirroring exercise I remind participants of these limitations – namely that the story we hear may not be true to the story told and indeed the story told may not be the story the teller intended to tell. This has the effect of easing any concerns participants may have about their personal ability to retell the stories that they hear. I also remind participants that as the facilitator I am there to support the retelling. I also explain that I will be taking notes at the completion of the mirroring exercise as each X tells their partner Y's story aloud to the group.

When it comes to the process of writing up after each session I write each participant's story in the first person. This allows me to integrate any original words or phrases the teller has shared whilst also making it very clear that the story is told from the perspective of the participant. Given each session is relatively short with up to six participants, the resulting transcripts are also quite short. Sarah's transcript is a good example:

During the War, when the Germans came to my native Belgium we had to capitulate. On 6 June 1945 we heard that the Allies had landed in France. There was a great celebration. Me and my family were in the countryside, staying at my grandparent's home. Brussels had been liberated the week before, we were now waiting for our turn.

The day we were liberated there was an electricity cut. The first we had for the whole war. First there came the Germans into the village on stolen bikes – we knew they were stolen because of their number plates. They came to our home. They wanted food. We fed them as quickly as we could, they lit the table with a light from their bikes. When they left they thanked us and as they went they muttered 'wir werden zuruck kommen' – we will come back. We understood their mutterings as we had had to learn German in school from the time of the Occupation. German language, approved version new atlases and new text books with the approved version of history had all been compulsory.

Next thing we heard was the planes. They were flying overhead, so low we could see the pilots and wave at them, they were American. The hens and the dogs in the village were terrified. They rushed into the stables away from the noise. Next came a

deep rumbling sound. It was the tanks. As they got closer we could see that they were American and we asked where they were headed, the answer Berlin.²⁵

The key point here is that the transcript is the story as told by the teller incorporating any inaccuracies and personal opinions. Naturally there is no reason why a facilitator should not go one step further and include relevant supporting images they may find online provided they explain to the participant that they will be doing this and then ask for their approval to insert it into the text. Equally the participant must be given the opportunity to request its removal. For the facilitator with the time and resources, inserting illustrations can add to the end product. On one occasion participants were telling stories relating to the senses. We started to consider the sense of sound and this led naturally to songs at which point Laura led a short chorus of the 'ABC song' which she used to sing along with her friends at the Saturday morning cinema club. She stumbled a little on the words for the verses but remembered every word of the chorus. The facilitator on that occasion went ahead after the session and found the full lyrics. Laura was delighted to see them reprinted in her personal story file.

On another occasion, again looking at the senses, we came to the sense of taste. Jean shared with us her love of baking and how although she can no longer eat the cakes she bakes, she enjoys watching others devour them. Jean provided a recipe for all members of the group and the following week arrived with a cake for us to share, it was delicious. We fondly refer to the cake as Jean's sponge cake.



Image 1: Jean's Cake. © 2015, SS4WB. Courtesy of SS4WB.

Jean's Victoria Sponge Cake

8oz self-raising flour

+

1 teaspoon baking powder

Sweep these together

8oz butter and margarine

+

8oz caster sugar

Beaten well together till light

4 large eggs

Add eggs one at a time and a teaspoon of flour

Add sieved flour

Put into 8" sandwich tin, well-greased, bottom and sides covered with a little flour

Heat oven to 160 degrees

Add to tins and cook for 20 minutes.

Check if ready by feeling the top of the cake. If it is firm and coloured gold, leave in tins for at least 10 minutes then turn out.²⁶

Making it clear to participants that they have complete control over the process at a time when many other decisions and actions may be very much out of their personal control goes a long way to encouraging the feelings of wellbeing.²⁷

D.3 Ownership

Since we are working with individuals with limited life expectancy, there must be an acknowledgement that the workshop participants may die during or shortly after their participation in the life stories workshops. Given also that there is no supporting research or corroboration of the facts contained in the stories it may be possible that the content of the stories is not appropriate for view by others. It is also to be expected that family members may want to see the stories. However it cannot be assumed that the teller wanted them shared. This dilemma can be pre-empted by using a simple consent form at the start of the workshop series. Participants are asked to complete a short form considering who can or cannot have access to the printed stories:

You will be presented with a story file containing your stories at the end of the workshop series. Please indicate what you would like done with the electronic copy of the document:

- Delete it immediately;
- Make copies available to my immediate family on their request;
- Automatically make copies available to my immediate family;
- Make copies available to (hospice) staff on their request;

-
- Automatically make copies available to (hospice) staff.²⁸

Addressing this situation at the start of the workshop process also minimises any anxiety the participant may have about the end recipient(s) of the stories. In the early stages of my work, before I had introduced a system to address the point, I was often asked by the patient about the intended recipient of the stories; were they for the vicar or the hospice marketing team? The answer of course was neither. By reassuring the patient that they own the story and control its distribution, this liberates them to tell. However, all of the stories referred to in this chapter and in any training work I undertake have been reproduced with the permission of their owner and pseudonyms have been used to preserve privacy.

5. Storytelling and Trauma

The process of life storytelling naturally triggers a series of memories and emotions. These are generally good and positive. Nora, a participant in the evaluation study acknowledged:

It was amazing what it brought back, it was absolutely fascinating and so many things came out that you'd completely forgotten... it was good because you remembered people you were fond of and hadn't thought about you know for sixty years and it's good to do that.²⁹

A. Support for Participants

Not all the memories in the course of a storytelling session will be positive. Supporting the group is crucial particularly where the facilitator is not a trained counsellor. Running the sessions in a group format encourages self-censorship with participants sharing only the stories they wish to be heard. Avoiding a linear storytelling model helps to minimise opportunities for comparison and negative self-reflection. However, there are still times where a participant may find themselves drawn into an uncomfortable space potentially after the session as they reflect upon what was told. The clear provision of access to professional support is imperative. I identify the *go to* individual on my workshop welcome sheet which is distributed in the first session:

EMOTIONAL SUPPORT

Our aim is to offer workshops which are uplifting with participation being a positive experience. The group is not arranged as a therapeutic experience. However sometimes during this process stories can evoke strong feelings we had forgotten. If this occurs there is support there for you. It can be helpful to talk

this through with an experienced health care professional, please contact (name, title and contact information).³⁰

B. Support for the Facilitator

Support should not be limited to workshop participants. Facilitators also need help. Working with patients at end of life raises the probability that participants may die in the course of the programme or shortly thereafter. Working with them and their stories means a strong bond may be built in a relatively short space of time. Their death, though not unexpected may also be difficult to deal with. Also, the subject matter of some of the stories can become a little morbid!

I have already referred to the session where discussion turned to the subject of coffins and my relief that I had a supervisor to turn to. Not so lucky was the film and audio biographer whom I met recently. She has been visiting hospices recording the stories of patients from their beds. Her work is fantastic but she has no emotional/clinical supervision. I was not surprised when she freely admitted that she often retires to the ladies loo to weep at the end of the day. Access to supervision for both patient and facilitator is something I cannot over emphasise.

6. Variations on the Programme

At the time of writing I have trained over 150 palliative care practitioners in the use of storytelling techniques and have personally recorded over a hundred life stories. I have no way of knowing how many stories have been recorded by those that I have trained. My hope for patients is that the process of participating in a life stories workshop will be the first step towards telling and sharing their life stories to others thereby going some way towards dealing with the eulogy situation. Feedback suggests that this is certainly happening with patients going on to write their own short stories, paint, make films and have refreshed conversations with their nearest and dearest. Jane started painting again having avoided her paintbrushes following her diagnosis a decade earlier. Michael wrote a full autobiography for his grandchildren.

In the same way I expressly encourage the practitioners I train to interpret and use the story sharing skills in the way that works best for them. The variety of ways they have gone on to work with life stories include:

- Establishing off site storytelling groups in the community;
- Offering storytelling for bereaved families;
- Working with children who have been bereaved;
- Producing individual films and sound recordings of patients telling their stories;
- Running groups linking patients and volunteers to share their stories;
- Offering regular drop in story sessions;
- Training for all staff working with patients to empower them to find another way to start a conversation.

One of the most unexpected uses for group storytelling has been as part of in-house staff development programmes. Group facilitators have reported back on the new bonds built and existing ones strengthened by actively encouraging staff together to share their life stories. I suppose that we shouldn't be overly surprised by this, after all, telling stories is part of what makes us human.³¹



Image 2: Dancing in Cassiobury Park by Jane. © 2015, SS4WB.
Courtesy of SS4WB

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Notes

¹ Jane Youell and Alison Ward, *Sharing Stories for Wellbeing: An Evaluation*. (Northampton: Institute of Health and Wellbeing, 2015), 9.

² Pam Morrison and Annie McGregor, *Making and Sharing Meaning Out of Terminal Illness*.

³ 'Banksy'. *Wikiquote*, Viewed 8 November 2016, <https://en.wikiquote.org/wiki/Banksy>.

⁴ Marilyn Kirshbaum, Ian Carey, Brigid Purcell and Seamus Nash, 'Talking About Dying and Death: A Focus Group Study to Explore a Local Community Perspective', *Nursing Reports* 1.1 (2011): 29-34.

⁵ Eagles, 'Hotel California', *Hotel California* (Asylum, 1977).

- ⁶ Jeffery Kottler, *Stories We've Heard, Stories We've Told: Life-Changing Narratives in Therapy and Everyday Life* (Oxford: Oxford University Press, 2015).
- ⁷ Extract from Miranda Quinney supervision, 2011. Contemporaneous note following supervision.
- ⁸ John W. Creswell, et al., 'Advanced Mixed Methods Research Designs', *Handbook of Mixed Methods in Social and Behavioral Research*, ed. Abbas Tashakkori and Charles Teddlie (Thousand Oaks, CA: Sage, 2003), 209-240.
- ⁹ Youell and Ward, *Sharing Stories for Wellbeing: An Evaluation*, 7.
- ¹⁰ Mary Ann Boyd, *Psychiatric Nursing: Contemporary Practice* (Philadelphia: Lippincott, Williams and Wilkins, 2005).
- ¹¹ Youell and Ward, *Sharing Stories for Wellbeing: An Evaluation*, 9.
- ¹² Kathrin Ohnsorge, Heike Gudat and Christoph Rehmann-Sutter, 'What a Wish to Die Can Mean: Reasons, Meanings and Functions of Wishes to Die, Reported from 30 Qualitative Case Studies of Terminally Ill Cancer Patients in Palliative Care', *BMC Palliative Care* 13.38 (2014): 1-4.
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- ¹⁴ Youell and Ward, *Sharing Stories for Wellbeing: An Evaluation*, 13.
- ¹⁵ Rebecca Redhouse, 'Life-Story: Meaning Making through Dramatherapy in a Palliative Care Context', *Dramatherapy* 36.2-3 (2014): 72-78.
- ¹⁶ Extract from Sharing Stories for Wellbeing Session, 2015.
- ¹⁷ Jennifer De Jong and Linda E. Clarke, 'What Is a Good Death? Stories from Palliative Care', *Journal of Palliative Care* 25.1 (2009): 61-67.
- ¹⁸ Youell and Ward, *Sharing Stories for Wellbeing: An Evaluation*, 17.
- ¹⁹ Monica Prendergast and Juliana Saxton, *Applied Drama: A Facilitator's Handbook for Working in Community* (Bristol: Intellect, 2013).
- ²⁰ Extract Training Session: Sharing Stories for Wellbeing, 2016.
- ²¹ Extract Sharing Stories for Wellbeing Workshop, 2015.
- ²² Extract Miranda Quinney Training Notes, 2015.
- ²³ Extract from Evaluation Interview with Lisa, Patient, 2015.
- ²⁴ Youell and Ward, *Sharing Stories for Wellbeing: An Evaluation*, 16.
- ²⁵ Extract Story Transcript, Sarah, 2013.
- ²⁶ Sharing Stories for Wellbeing storytelling session, personal communication, Anon, 2015.
- ²⁷ Ohnsorge, Gudat and Rehmann-Sutter, 'What a Wish to Die Can Mean', 8.
- ²⁸ Extract Miranda Quinney Training Notes, 2015.
- ²⁹ Extract from Feedback Session, 2015.
- ³⁰ Extract Miranda Quinney Training Notes, 2015.
- ³¹ Tineke A. Abma, 'Learning by Telling, Storytelling Workshops as an Organisational Learning Intervention', *Management Learning* 34.4 (2003): 221-240; Arthur Ransom, *A History of Storytelling: Studies in the Development of Narrative* (Classic Reprint) (Hong Kong: Forgotten Books, 2012).

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